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Feature Story

At Last: A National Test of Taste and Smell

By Robin Latham

The four trailers in two neat rows temporarily resting in a hotel parking lot in suburban Maryland don't look like much, but they may be the most valuable part of a decades-long initiative to chart the health and well-being of the American public. Put together, the four 52-foot trailers make up a moveable state-of-the-art medical facility gathering data for the National Health and Nutrition Examination Survey (NHANES). Administered by the Centers for Disease Control and Prevention (CDC), NHANES is the only nationally representative health survey in the United States that combines in-person interviews with physical examinations. Now, for the first time in the six decades it has been in operation, NHANES, thanks to support from the NIDCD, is gathering information about taste and smell function in adult Americans.

Thanks to NHANES' careful collection of health and health behavior data, and its analyses by epidemiologists and biomedical researchers, scientists have been able to substantiate the dangers of second-hand cigarette smoke, for example, and the health consequences of exposure to lead-based paint. If you have children, you're well acquainted with NHANES, whose data built the growth charts your pediatrician uses to determine how well your baby is developing compared to other babies of the same age.

Although NHANES has included a hearing test for decades, the NIDCD has been trying to add assessments for taste and smell function since 1997, when it first began working with the National Center for Health Statistics (NCHS) to develop reliable tests.



"Taste and smell, our chemosensory perceptions, form the basis for what we choose to eat or drink," says Howard Hoffman, M.A., program director of epidemiology and statistics at the NIDCD, and one of the prime movers of the initiative to include taste and smell tests in the NHANES battery. "Does the ability to taste and smell impact nutrition? I would say so, but in what ways and to what degree remains uncertain."

NHANES has been in operation since the 1960s as an initiative of NCHS. In 1987, NCHS became one of the components of the CDC, and in 1999, NHANES became a continuously operating survey, administered in two-year cycles.

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To add your name to
our e-mail list, visit
<http://www.nidcd.nih.gov/health/inside/>

The half-day NHANES exam includes the usual types of tests you'd find in a standard physical exam, such as those that measure height, weight, blood pressure, and cholesterol levels, but it also includes a thorough nutritional assessment using sample size bowls, plates, and cups to help people more accurately describe what, and how much, they eat. In a separate home visit, an NHANES worker uses a carefully crafted questionnaire to document day-to-day activities, lifestyle behaviors, symptoms of illness, and chronic health conditions. Corresponding census data provides demographic and socioeconomic information.

One of the driving forces behind this push for the inclusion of taste and smell measures in NHANES was the sheer lack of knowledge available about taste and smell dysfunction in the adult American population. Local community-based studies estimated that up to 15 percent of adults might have a smell or taste problem, but a representative nationwide exam-based survey had never been conducted.

By adding tests that measure taste and smell function to the nutritional information NHANES already collects, epidemiologists and biomedical researchers will be able to take a closer look at the role of taste and smell in nutrition and health. Just as important, thanks to the physical exams and detailed medical histories NHANES technicians collect, researchers will be able to explore associations between taste and smell dysfunction and medical conditions such as high blood pressure and diabetes, as well as brain disorders such as Parkinson's and Alzheimer's diseases, which are characterized by an early loss of smell.

"The potential for this is enormous," says Susan Sullivan, Ph.D., the NIDCD's program director for smell and taste research. "We haven't had a national survey like this before, so we have no idea what novel and unanticipated findings may come out of this. With objective data to look at as far as prevalence goes, we can start to test hypotheses about risk factors for, and the consequences of, impairment in the ability to taste or smell."

In 2004, the NIDCD made a strategic decision to tag a taste test onto the ongoing Beaver Dam Offspring Study (BOSS), which was conducted among a group of more than 5,000 residents of Beaver Dam, Wisconsin. The test used filter paper impregnated with salty, sweet, sour, and bitter substances to test taste sensitivity.

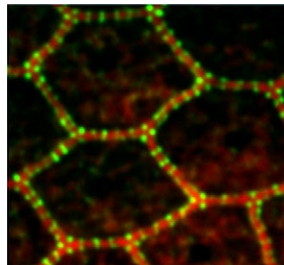
"The NCHS wanted proof that any tests we proposed using would be feasible in a large-scale epidemiological study," says Mr. Hoffman. "Once they saw that the Beaver Dam study was able to implement reliable tests of both taste and smell function, they were sold."

The NIDCD continued work on a smell test that used scratch and sniff cards of common food smells, such as garlic, chocolate, and strawberry, and unpleasant or warning odors, such as gasoline, smoke, and natural gas. The taste test was refined to use bitter and salty oral solutions applied to the tip of the tongue and in the whole mouth, a process graphically described as "rinse, sip, and spit."

In January 2012, the tests were added to NHANES on a pilot basis, and in January 2013 the tests were adopted into the NHANES survey. The NIDCD continues to support the effort with funding for monitoring and assuring the quality and reliability of the exams and questionnaire in the field. Data collection will continue through December 2014, at which point it's expected that more than 4,000 adult Americans, 40 years and older, will have been evaluated. Questions about problems with the ability to smell and taste have also been added to the at-home questionnaire so that researchers will have a full complement of exam-based and self-reported data to work from when the full data set is released in 2015.

Recent Research and News

Chain Reaction: NIH Researchers Find Dynamic Ties Between Epithelial Cells



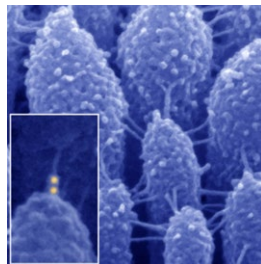
A new finding from researchers supported by the NIDCD and the National Heart, Lung, and Blood Institute (NHLBI) has uncovered a never-before seen method of intracellular physical communication

among epithelial cells in the inner ear. The finding could offer scientists a potential new pathway for developing ways to treat hearing loss and diseases in many different organ systems. Read the full article at <http://www.nidcd.nih.gov/news/releases/13/Pages/061213.aspx>.

Researchers Discover Mutations Associated with Perrault Syndrome, a Rare Hereditary Form of Deafness and Ovarian Failure

An international team of researchers partially supported by funding from the NIDCD has identified three genetic variants associated with a rare form of sensorineural hearing loss known as Perrault syndrome. The mutations, found in the CLPP gene, interfere with protein regulation essential to the normal function of mitochondria—cellular structures that operate as energy generators in cells. Perrault syndrome is a rare autosomal recessive condition characterized by moderate to severe sensorineural hearing loss at birth in both males and females. Read more at <http://www.nidcd.nih.gov/news/releases/13/Pages/032813.aspx>.

Researchers Discover Two-Step Mechanism of Inner Ear Tip Link Regrowth



A team of NIDCD-supported researchers has been the first to show, in mice, an unexpected two-step process that happens during the growth and regeneration of inner ear tip links. Tip links are extracellular tethers

that link stereocilia, the tiny sensory projections on inner ear hair cells that convert sound into electrical signals, and play a key role in hearing. The discovery offers a possible mechanism for potential interventions that could preserve hearing in people whose hearing loss is caused by genetic disorders related to tip link dysfunction. Read more at <http://www.nidcd.nih.gov/news/releases/13/Pages/061113.aspx>.

Scientists Identify Critical Link in Mammalian Odor Detection

Researchers partially funded by the NIDCD have identified a protein that is critical to the ability of mammals to smell. Mice engineered to be lacking the Ggamma13 protein in their olfactory receptors were functionally anosmic – unable to smell. The findings may lend insight into the underlying causes of certain smell disorders in humans. Read more at http://www.monell.org/news/news_releases/monell_scientists_identify_critical_link_in_mammalian_odor_detection.

Researchers Identify Forerunners of Inner-Ear Cells that Enable Hearing

Researchers at the Stanford University School of Medicine, supported in part by the NIDCD, have identified a group of progenitor cells in the inner

ear that can become the sensory hair cells and adjacent supporting cells that enable hearing. Studying these progenitor cells could someday lead to discoveries that help millions of Americans suffering from hearing loss due to damaged or impaired sensory hair cells. Read more at <http://med.stanford.edu/ism/2013/february/ear-hair.html>.

NIDCD Highlights

NIDCD Establishes New Center for Aphasia Research

The NIDCD recently awarded a five-year, \$12 million clinical research center grant to Northwestern University in Chicago to establish the Center for the Neurobiology of Language Recovery, a multidisciplinary, multi-institute program devoted to research on aphasia.

Aphasia is a communication disorder that impairs the expression and understanding of language, reading, and writing. It can occur after a stroke or other brain injury. More than a million people in the United States currently have aphasia and, according to the National Aphasia Association, an additional 100,000 Americans every year acquire aphasia from strokes and other causes.

The new center is led by Cynthia Thompson, Ph.D., the Jean and Ralph Sundin professor of communication sciences at Northwestern University. Dr. Thompson's work focuses on brain plasticity and language recovery in people with aphasia, particularly those with agrammatic aphasia, which affects the ability to understand and produce sentences.

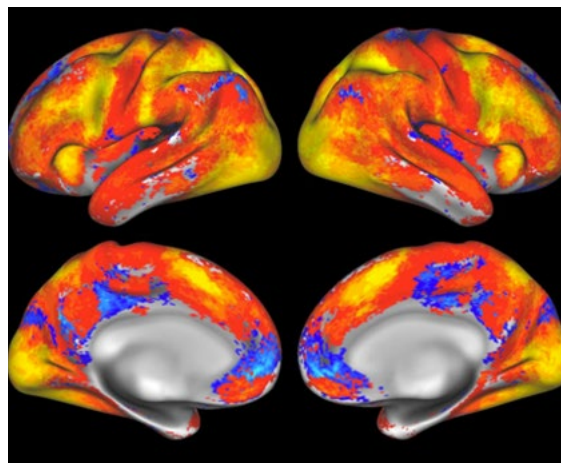
The Center is also supporting related projects at Harvard University, Boston University, and The Johns Hopkins University.

Work from all four projects will be used to design and test new treatments. The researchers plan to enroll into studies more than 200 people with aphasia and expect to generate a large database of results for other researchers in the field to use. A major focus of the Center will be identifying biomarkers of recovery—whether imaging parameters such as blood flow to the brain or brain activity while at rest can help predict who will eventually regain their communication abilities.

"The collaboration among these multidisciplinary teams will serve as a national resource for aphasia research, which could significantly accelerate the scientific discoveries that will lead to better treatment for the thousands of people who develop the condition each year," says Judith A. Cooper, Ph.D., deputy director of the NIDCD. "It is critical to have an improved understanding and find better treatment modalities."

NIH Jumpstarts the Future of Neuroscience with the BRAIN Initiative

On April 2, President Barack Obama announced a proposal for an ambitious new neuroscience research initiative called the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative (<http://www.nih.gov/science/brain/index.htm>). In addition to the National Institutes of Health (NIH), the BRAIN Initiative will also include participation from the Department of Defense's Defense Advanced Research Projects Agency (DARPA), the National Science Foundation (NSF), and private foundations including the Howard Hughes Medical Institute and the Allen Institute for Brain Science.



A map of overall task-fMRI brain coverage from the seven tasks used in the Human Connectome Project. Yellow and red represent regions that become more active in most participants during one or more tasks in the MR scanner; blue represents regions that become less active.

Source: D.M. Barch for the WU-Minn HCP Consortium

Neuroscience has reached a point where radical new discoveries are being held back by a lag in the technology needed to understand how complicated neural networks in the brain work, explained NIH Director Francis S. Collins, M.D., Ph.D. in a White House Q&A session (available at <http://www.whitehouse.gov/blog/2013/04/02/open-questions-brain-initiative>).

"This initiative is an idea whose time has come. We have learned over the course of years how to record from individual neurons and to see what happens when they are being activated, and to learn a bit about how they're connected. We know there's a hundred billion [neurons] in the human brain, and that each one of those makes thousands of connections. But we haven't been able to really understand what's going on in real time in the circuits in the brain that control important things like the visual system, like memories, like even consciousness," said Dr. Collins.

"We would love to be able to take advantage of new technologies that are just now being invented . . . and utilize that to build a new foundation upon which we can build new insights into Alzheimer's disease, epilepsy, Parkinson's disease, autism, schizophrenia, traumatic brain injury, post-traumatic stress disorder (PTSD); all of these conditions that we know have their basic difficulties residing in the brain but where our tools for understanding them have been limited," he added.

While many diseases and disorders studied by the NIDCD have a structural basis—in physical defects or damage to the sensory organs—many also have a neurological origin, making the BRAIN Initiative timely for NIDCD researchers and grantees.

The NIH has committed \$40 million dollars to the initiative in Fiscal Year '14, to be channeled through the NIH Blueprint for Neuroscience Research (<http://neuroscienceblueprint.nih.gov>). This summer, an advisory committee to the NIH Director will define the goals and develop and multi-year plan, using feedback from the larger neuroscience community.

NIDCD'S Noisy Planet Campaign

Noisy Planet Community Outreach

Noisy Planet presenters from the NIDCD visit schools and community groups in the DC metro area to deliver an interactive and educational 45-minute presentation about how to protect hearing from noise-induced hearing loss, the only kind of hearing loss that is completely preventable. The Noisy Planet team has reached more than 8,000 students since 2010. After a recent visit to South Lake Elementary School in Gaithersburg, Md., third grade teacher Elena Ramos thanked us by writing, "You don't have any idea how excited our third graders were about your and Mr. Miranda's presentation. I am sure that they learned a lot and they know, now, how to protect their hearing. All the teachers in our third grade team are very appreciative of your effort to keep our students engaged and well informed."

Noisy Planet at NIH's Take Your Child to Work Day and Earth Day Events

Earth Day and Take Your Child to Work Day coincided this year on the NIH campus in Bethesda, Md., and employees had the opportunity to bring their children to many fun activities and demonstrations. For Take Your Child to Work Day, children had the chance to participate in two sessions of the Noisy Planet presentation, which is typically offered for schools and community groups, and learned what sound is, why hearing protection is important, and how to protect their hearing in three easy ways: by walking away, wearing hearing protectors, or turning down the volume.

The theme for this year's Earth Day celebration was "Healthy Planet/Healthy People." Noisy Planet arrived with Kirby, a tween-sized mannequin with an integrated sound level meter that tested the volume on children's MP3 players. Participants also spun the Noisy Planet wheel to test their knowledge about hearing and hearing protection.

Are you looking to stay current on the latest tips to protect your hearing? Join Noisy Planet on Facebook at <http://www.facebook.com/NoisyPlanet> or visit the website at <http://www.noisyplanet.nidcd.nih.gov>.



A young girl gives the Noisy Planet wheel a spin. Kirby, the child-size mannequin, is on the left.

Beyond NIDCD: News from Other Organizations

CASANA Releases Request for Applications for Childhood Apraxia of Speech Research

The Childhood Apraxia of Speech Association of North America (CASANA) has issued a Request for Applications from scientists whose focus is clinical research aimed at the diagnosis and treatment of children with apraxia of speech (CAS). Other areas of interest can include methods for early identification, and approaches that include both biophysical and behavioral evidence. CASANA has expanded the program to include consideration of applications from Ph.D. candidates who are investigating CAS for their dissertation. Applications are due August 1, 2013. For more information, see http://www.apraxia-kids.org/wp-content/uploads/2013/03/CASANA_RFA_2013_Final.pdf.

American Tinnitus Association Offers Sound Mixer to Aid Sleep

The American Tinnitus Association offers a free sound mixer tool to create customized soothing sounds to help you find relief from tinnitus for better sleep. Make your own mix from a palette of

more than 30 soothing natural sounds. Make your mix online and save it for future listening, or share it with friends and family. Go to the ATA website at <http://www.ata.org/sound> to learn more.

The Stuttering Foundation Launches Three New DVDs

The Stuttering Foundation recently announced the release of three new DVDs:

Evidence-Based Practice and Practice-Based Evidence: Closing the Gap

Nan Bernstein Ratner, Ed.D., discusses current debates about the best practices in fluency treatment.

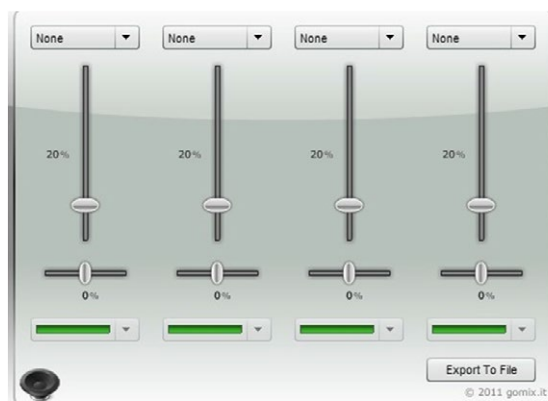
Avoidance Reduction Therapy in a Group Setting

Vivian Sisskin, M.S., CCC-SLP, walks clinicians through methods of group therapy while providing the nuts and bolts of Avoidance Reduction Therapy. Demonstrations offer ideas for activities and assignments that can lead to spontaneous, forward-moving communication.

Autism Spectrum Disorders and Stuttering

Vivian Sisskin, M.S., CCC-SLP, summarizes the current literature about disfluency in autism and provides basic principles to aid in differential diagnosis and treatment planning.

To order the DVDs, visit the Stuttering Foundation website at <http://www.stutteringhelp.org/>.



New Resources

NIH and NIDCD on Twitter

On May 7th, the director of the National Institutes of Health, Frances S. Collins, M.D., Ph.D., posted a Twitter request that generated thousands of responses and retweets from researchers and members of the American public.

You can send your thoughts on the impact of the sequester on biomedical research to directly to Dr. Collins on Twitter using the hashtag #NIHSequesterImpact.

We'd also like to hear from you about how you think the sequester will impact the progress research in our core areas of: hearing, balance, taste, smell, speech, and language. You can reach us via Twitter or email us.



A follow-up tweet posted by Dr. Collins later that day continued:



To follow Dr. Collins on Twitter, go to <http://twitter.com/NIHDirector>. You can follow the NIDCD (@NIDCD) on Twitter at <http://twitter.com/NIDCD>.

For more information about Dr. Collins and the NIH, visit the NIH Director's blog at <http://directorsblog.nih.gov/>.

Put a Plug in It!

Need an easy way to show people how to protect their ears from noise-induced hearing loss using ear plugs? Visit the Noisy Planet website (<http://www.noisyplanet.nidcd.nih.gov>) and download a graphic that shows how to properly insert ear plugs for hearing safety.



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